# IN THE UNITED STATES COURT OF APPEALS FOR THE EIGHTH CIRCUIT

Little Rock Family Planning Services, et al., Plaintiffs-Appellees,

v.

Leslie Rutledge, in her official capacity as Attorney General of the State of Arkansas, et al., *Defendants-Appellants*.

Appeal from the United States District Court for the Eastern District of Arkansas, No. 4:19-cv-00449-KGB, The Honorable Kristine G. Baker

Addendum of Brief of *Amici Curiae* State of Missouri and 16 Other States

Eric S. Schmitt

Attorney General

D. John Sauer, MO Bar No. 58721 Solicitor General Julie Marie Blake, MO Bar No. 69643 Deputy Solicitor General P.O. Box 899 Jefferson City, MO 65102 Tel: (573) 751-8870

Fax: (573) 751-0774 Counsel for Amici States

E-mail: John.Sauer@ago.mo.gov

Appellate Case: 19-2690 Page: 1 Date Filed: 11/06/2019 Entry ID: 4849451

## IN THE UNITED STATES DISTRICT COURT FOR THE WESTERN DISTRICT OF MISSOURI CENTRAL DIVISION

REPRODUCTIVE HEALTH SERVICES	)
OF PLANNED PARENTHOOD OF THE	)
ST. LOUIS REGION, INC., et al.,	)
	)
Plaintiffs,	)
V.	) Case No. 2:19-cv-4155
<b>v.</b>	) Case No. 2.17-cv-4133
MICHAEL L. PARSON, in his official	)
capacity as Governor of the State of	)
Missouri, et al.,	)
	)
Defendant.	

#### **DECLARATION OF MARTIN J. McCAFFREY, M.D.**

Pursuant to 28 U.S.C. §1746, I, **MARTIN J. McCAFFREY, M.D.**, duly affirm under penalty of perjury as follows:

- 1. I am over 18 years of age, have personal knowledge of the matters set forth herein and am competent to make this Declaration. The opinions I render in this Declaration are my own, and do not represent any other person or group. I have reviewed the plaintiffs' Complaint in the above-captioned case.
- 2. I am a physician licensed to practice medicine in the State of North Carolina. I am board certified in the specialty of neonatology. I attended the University of Connecticut as an undergraduate student and graduated with a B.S. degree in Biology in 1982. I completed my medical degree at Albany Medical College and graduated in 1986. I entered pediatric residency training at the Naval Medical Center in San Diego ("NMCSD") in 1989. I was assigned as a general pediatrician to Naval Hospital Guam. After completing a three-year tour of duty in Guam, I entered neonatal fellowship training in 1992 at the University of North Carolina at Chapel Hill. I

completed my neonatal training in 1995 and was assigned as a neonatologist to NMCSD. This

final tour of duty lasted eleven years. During this period, I served as the Director of Neonatal

Intensive Care for NMCSD and the Consultant to the Navy Surgeon General for Neonatal

Affairs. After retiring from the Navy in 2006, I was appointed as an Associate Professor in the

Division of Neonatal Perinatal Medicine at the University of North Carolina at Chapel Hill. I

became the Director of the Perinatal Quality Collaborative of North Carolina and was promoted

to Professor in the Department of Pediatrics in the Division of Neonatal-Perinatal Medicine in

2011. Attached hereto as Exhibit 1 is a true and correct copy of my curriculum vitae.

3. This declaration contains my expert opinions, based on my education, experience,

training, and review of the medical literature, and I hold the opinions in this declaration to

areasonable degree of medical certainty. In this declaration, I do not speak on behalf of my

employer or any institution or organization with which I am affiliated.

4. To the best of my knowledge, no opinion which I have previously rendered in

any legal matter has been disqualified or excluded by any court.

5. I have been actively practicing neonatology in a Level IV neonatal intensive care

unit ("NICU") since 2006. Level I facilities provide basic newborn care for infants who are

presumed to be of low risk for complications. Level II facilities care for stable or moderately ill

newborn infants who are born at ≥32 weeks' gestation or who weigh ≥1500 g at birth with

problems that are expected to resolve rapidly and who would not be anticipated to need

subspecialty-level services on an urgent basis. Level III NICUs provide long-term care and

ongoing assisted ventilation to infants who are born at <32 weeks' gestation, weigh <1500 g at

birth or have medical or surgical conditions. Level IV NICUs care for the same infants as a

Level III NICU, with the added requirement that Level IV facilities also have the capability for

surgical repair of complex conditions (e.g, congenital cardiac malformations that require

cardiopulmonary bypass with or without extracorporeal membrane oxygenation). Although many

infants born with Down syndrome do not require NICU care, my NICU practice does include the

care of infants with Down syndrome requiring neonatal intensive care.

6. Every neonatology practice I have been part of has required me to provide prenatal

counseling to mothers and families of infants with difficult prenatal diagnoses. Such consults are

frequently related to the care of unborn infants with Trisomy 21 or Down syndrome.

7. Formerly as a general pediatrician, and more recently as part of my neonatology

duties, I regularly have and do provide care to children with Down syndrome in the outpatient

clinic setting.

8. Down syndrome is a congenital condition resulting from a chromosomal

abnormality, specifically three copies of chromosome 21. It is the most common of the disorders

manifested by an extra chromosome (aneuploidy). Down syndrome is characterized by varying

degrees of intellectual disability. It also involves some physical abnormalities (including low

muscle tone, small stature, flatness of the back of the head, an upward slant to the eyes) and

increased health risks (of heart defects, childhood leukemia and Alzheimer's disease). The average

life expectancy for an individual with Down syndrome is now 47 years.<sup>1</sup>

9. The Declaration of Dr. Bebbington states, "As a result of my education, training,

and clinical work, I am very familiar with Down syndrome and the methods of screening and

testing for the condition during pregnancy." The Declaration continues, "Down syndrome is a life-

long syndrome that can manifest as a range of severe medical conditions. Medical conditions

commonly seen in individuals with Down syndrome include intellectual disability and congenital

heart disease. These associated conditions can also shorten life expectancy. Caring for individuals

with Down syndrome typically requires a multidisciplinary approach that extends from birth and

into, and throughout, adulthood. Many individuals with Down syndrome require significant care

into adulthood."

10. "Lifelong", "severe", "intellectual disability", "shorten life expectancy", and

"significant care throughout adulthood" are not the balanced descriptions that would be applied to

an individual whose life, while challenging due to disabilities, would be viewed as valuable. This

is not balanced prenatal counseling. Nor is it the description that would be offered by a practitioner

experienced in the care of individuals with Down syndrome. This is consistent with the judgmental

terminology offered by physicians who consciously or not, perpetuate the subtle discrimination

that diminishes the value of lives of those with Down syndrome.

11. Dr. Bebbington reports that congenital heart disease is one of two medical

conditions which can shorten life expectancy in patients with Down syndrome. Certainly

congenital heart disease can be challenging, and may require surgical repair, but for the common

cardiac anomalies in Down syndrome, when surgery is required, it is generally successful. The

cardiac anomalies which may occur in Down syndrome patients also occur in non-Down syndrome

patients. In the latter group it would be difficult to find a pediatric provider who would cite the

presence of such an anomaly as severe, shortening life expectancy and use it as justification for

termination of pregnancy. As for comparisons between the two groups, "CHD is present in

approximately 50% of patients with T21. AVSD repair is the most frequent cardiac surgery. After

AVSD repair, trisomy 21 patients have lower frequency of reoperation and have similar in-hospital

and long-term mortalities compared with non-T21 counterparts...In-hospital death for patients

with DS was significantly lower than that for patients without DS overall (1.9% versus 4.3%;

P<0.05)".<sup>2</sup>

12. The other specific example Dr. Bebbington reports as associated with a shortened

life span is intellectual disability. This statement contradicts the well documented history of Down

syndrome over the last six decades. It has actually been the discrimination against those with

intellectual disability manifested in depriving them of medical care that has led to shortened lives

for individuals with Down syndrome. The mean life expectancy for individuals with Down

syndrome in 1960 was 10 years. It has progressed to 47 years in 2007. Why? It was not until well

into the 1980s that the medical profession uniformly abandoned recommendations for

institutionalization and facilities such as the infamous Willowbrook were closed. These were

institutions in which Down syndrome individuals were neglected socially, nutritionally and

medically. It was also not until well into the later 1980s that the medical community began to

universally consider cardiac and other interventions and surgeries for infants with Down

syndrome, and abandoned recommendations for institutionalization. <sup>3,4</sup>

13. The literature documents significant delays in diagnosis of AV Canal, and failure

to offer repair despite acceptable levels of pulmonary vascular resistance, in Down syndrome

patients.<sup>5.6</sup> It was several high profile surgical cases, including the Baby Doe case, and

controversial publications regarding withholding of care in NICUs that led to political action

spearheaded by parent and disability rights groups, not physicians. These seismic societal shifts

forced the medical community to extend commonly accepted medical interventions to Down

syndrome patients.<sup>7,8</sup>

14. It is not hyperbole to state that the history of the medical establishment's approach

to Down syndrome over the last century has been dominated by discrimination. In this country

forced sterilization programs, the routine recommendation of institutionalization, and the denial of

medical care to those with complications related to Down syndrome were the rule. Not

uncommonly mothers were shielded from the knowledge that she had a child born with Down

syndrome and the child would be sent off to an institution after being told the child had died. The

horrors of the institutions over the years became more commonly known, yet still persisted.

Sterilization, lobotomies, experimental "treatments" and physical abuse were common at these

facilities.<sup>3,4</sup>

15. In 1973 Duff and Campbell published a landmark article in the New England

Journal of Medicine.<sup>5</sup> In it they detailed the deaths of 43 infants in the Yale University NICU

which occurred from 1970-1972 after treatment was discontinued due to "severe impairment." The

conditions included in this category were generalized as short bowel syndrome, cardiopulmonary,

meningomyelocele, other central nervous system, multiple anomalies and trisomies. While

specifics of all cases are not given, one case detailed is of an infant with Down syndrome and

duodenal atresia (a blockage of the small bowel which is easily repaired), and the decision of the

family that "surgery was wrong for their baby and themselves."

16. In generally commenting on their decisions to withdraw care, the authors

commentary invokes dehumanizing language which denies the humanity of these infants. They

also offer testimony that the care provided the disabled in institutions is horrific, though their

solution to the problem is to end the life of the child. "Regarding the infants, some contended that

individuals should have a right to die in some circumstances such as anencephaly,

hydranencephaly, and some severely deforming and incapacitating conditions. Such very defective

individuals were considered to have little or no hope of achieving meaningful "humanhood." For

example, they have little or no capacity to love or be loved. They are often cared for in facilities

that have been characterized as "hardly more than dying bins," an assessment with which, in our

experience, knowledgeable parents (those who visited chronic-care facilities for placement of their

children) agreed. With institutionalized well children, social participation may be essentially

nonexistent, and maternal deprivation severe; this is known to have an adverse, usually disastrous,

effect upon the child. The situation for the defective child is probably worse, for he is restricted

socially both by his need for care and by his defects. To escape "wrongful life," a fate rated as

worse than death, seemed right. In this regard, Lasagna notes, 'We may, as a society, scorn the

civilizations that slaughtered their infants, but our present treatment of the retarded is in some ways

more cruel."<sup>5</sup>

17. It was the determination of families and advocacy groups, as well as revelations

and exposes of the inhumanity of institutions, coupled with high profile medical cases of medical

neglect of children with Down syndrome (Baby Doe 1982 in Bloomington Indiana), and actual

reporting by physicians of their willingness to withhold care from the disabled, that led to the

reversal of most of the obvious discriminatory medical practices suffered by the Down syndrome

community for decades.<sup>9</sup>

18. The physician advising no intervention for the Down syndrome child with a

tracheo-esophageal fistula in the Bloomington case was the obstetrician who delivered the child.

Dr. Owens objected to the recommendations of the pediatricians that the baby be transferred to

Riley Childrens Hospital for life-saving surgery and instead offered the parents an alternative of

denying their baby feedings and hydration, allowing the baby to die.<sup>9</sup>

19. Dr. Owens passionately argued this case before a local judge and offered a later

statement to the Supreme Court in 1983 in a petition for a writ of certiorari for this case. His

statement included, "I insisted upon telling the parents, pointing out to the parents, that if this

surgery were performed and if it were successful and the child survived, that this would still not

be a normal child. That it would still be a mongoloid, a Down's syndrome child with all of the

problems that even the best of them have. That they did have another alternative which was to do

nothing. In which case the child probably live only a matter of several days and would die of

pneumonia probably. Some of these children, as I indicated in my testimony to Judge Baker, are

mere blobs. Some of them are. Most of them eventually learn to walk, and most of them eventually

learn to talk...This talk consists of a single word or something of this sort at best. I have never

personally known the true Down's syndrome child that was able to be gainfully employed in

anything other than a sheltered workshop, with constant supervision, in other words a child that

could be self-supporting. I've never heard of a Down's syndrome child that could live alone. They

require at best constant attention.... These children are quite incapable of telling us what they feel,

and what they sense, and so on."9

20. These changes were occurring through the 1980s, but as late as 1992 a publication

reporting on the changing attitudes of physicians towards Down syndrome noted that 15% of

pediatricians would support parents in not repairing duodenal atresia, a straightforward and low

risk surgery required in order to live, in a child with Down syndrome. <sup>10</sup>

21. One might conclude that given generally more equitable application of medical care

to individuals with Down syndrome over the last few decades, the recognition of the value of

special education programs, and the passage of the Americans with Disabilities Act, that the stain

of eugenic Down syndrome discrimination (and discrimination against others with intellectual

disabilities) has ended. It is true we are no longer living in a period of state sanctioned sterilization,

medically recommended institutionalization and denial of medical care. We have evolved far more

effective methods, however, to exercise discriminatory tendencies. We are now able to identify

the vast majority of Down syndrome infants in the womb and order their termination.

22. The 1980s saw the widespread introduction of prenatal screening for Down

syndrome. The screening techniques have included biochemical screening, and now maternal cell

free DNA screening, with confirmatory testing via amniocentesis or chorionic villous sampling.

The results of increasing spread and acceptance of prenatal genetic testing has led to significant

increases in the identification of unborn infants with Down syndrome and a subsequent increase

in their abortion rates. Increasing maternal age since the 1980s is a factor that is highly associated

with an increased incidence of Down syndrome pregnancies, and an increase in the number of

individuals with Down syndrome would be anticipated. "However, owing to the increased use of

prenatal screening and subsequent terminations, the live-birth prevalence has remained relatively

constant" in many countries.<sup>11</sup>

23. De Graaf et al estimated rates at which live births with DS were reduced as a

consequence of DS-related elective pregnancy terminations as 30% (95% CI: 27.3–31.9) for the

U.S. as a whole between 1996 and 2007. 12

24. Interest in "reducing the prevalence" of Down syndrome is not strictly a US

phenomenon. It is a world wide effort. A review of the history of prenatal screening states, "A

series of technical and conceptual developments over the last 4 decades have led to the widespread

introduction of prenatal screening programs. As a result, in countries with optimal screening

policies most NTD and common aneuploidy births can be avoided." Avoided? Reduced

prevalence? The only way conditions like Down syndrome can be avoided or have their prevalence

reduced is by aborting the baby.

25. Abortion rates of prenatally diagnosed infants with Down syndrome vary between

countries. What must be remembered is that even if overall numbers are unchanged, maternal age

has increased and would be expected to result in larger numbers of individuals born with Down

syndrome. Estimates are that in the United States there were 30% fewer individuals with DS

(2007), 12 50% fewer in the Netherlands (2015), 14 48% fewer in England and Wales (2008), 15 55%

fewer in Australia (2004), 16 94% fewer in Taiwan (2010), 17 and 55% fewer in China (2011). 18 This

is not the termination rate, this is the percent reduction in the Down syndrome population after

including calculations for estimated fetal loss for cases of Down syndrome that would have

miscarried.

26. Regarding actual abortion rates, in Denmark, first trimester screening has a very

high uptake (>90%) with abortion rates 90-95% after positive prenatal testing for Down

syndrome. <sup>19</sup> In Spain abortion rates are reported as 94% when there is a prenatal diagnosis of Down

syndrome.<sup>20</sup> Iceland has universal availability for genetic screening and rates of abortion are

similar to Denmark, approaching 100% for those undergoing testing.<sup>21</sup>

27. Some would dismiss the worldwide epidemic of abortions for cases of Down

syndrome as women exercising their reproductive autonomy and seeking to prevent the suffering

of a child in a world which will be unbearably cruel to their child. Even if this were the case,

ending the child's life as a perceived act of mercy is not the proper answer, but this perception of

the life of Down syndrome individuals is not borne out by the medical literature. The notion that

Down syndrome children lead a life of pain and suffering, destroying families, is simply untrue.

Skotko et al. have reported that the overwhelming majority of people with Down syndrome they

surveyed indicate they live happy and fulfilling lives.<sup>22</sup> Similarly, Skotko et al report the

overwhelming majority of parents surveyed are happy with their decision to have their child with

Down syndrome and indicate that their sons and daughters are great sources of love and pride.<sup>23</sup>

28. Dr. Bebbington states, "Counseling patients on fetal conditions is a crucial element

of my clinical practice involving fetal conditions, and I spend much of my time as a practitioner

counseling patients. When a patient and her family receive a diagnosis of a chromosomal

abnormality such as Down syndrome, it can be emotionally trying. The patient may reasonably

anticipate substantial responsibilities and unique obligations that can accompany raising a child

with such a condition, and that can accompany caring for that child into adulthood. Some patients

may have anxiety, concern, fear, or many other emotions in response to this diagnosis. In my role

as a physician, it is important that my patient feel comfortable expressing her thoughts and

concerns to me, so that I can provide appropriate, responsive, nondirective counseling."

29. Dr. Bebbington continues, "The patient's choice of how to proceed in light of a

diagnosis of a fetal condition, including Down syndrome, is entirely personal, informed by

considerations unique to her. They can include, among other things, consultation with her family,

her financial circumstances, anticipated impact on her ability to care for existing children, and a

host of other factors."

30. Dr. Bebbington well describes key factors considered by mothers and partners in

deciding to abort their child with Down syndrome. Why is he unable to mention anything positive

about the impact of the lives of Down syndrome individuals? While the literature clearly

demonstrates that individuals with Down syndrome have medical conditions which are treatable,

have a good quality of life and are loved by their families, Dr. Bebbington throughout his statement

chooses to highlight the negative impact a child with Down syndrome can have on a family in

making the case to support the family's quality of life as having primacy over the good of the child

in deciding to peruse abortion. In stating that "decision-making around a diagnosis of Down

syndrome is complex, deeply personal, and highly dependent on an individual family's

circumstances, values, resources, and needs," Dr. Bebbington is stating that the decision to abort

an infant with Down syndrome is a decision that denies the infant any rights, not only the right to

life but any protection from discrimination based on potential disability, and gives supremacy to

the personal good of the family.

31. Dr. Bebbington offers a discouraging narrative for families dealing with a Down

syndrome child. "In my years of practice, I have observed how a diagnosis of a fetal condition can

take a toll on a family. I have seen families torn apart over the emotional strain of the diagnosis,

and also over the emotional strain of being forced to carry a pregnancy to term when the patient

and her family desired termination. I have seen families agonize over whether and how to parent

a child with a severe condition, while still providing for existing children with limited means. The

only comment made by Dr. Bebbington regarding Down syndrome that can be construed as at best

neutral is, "And I have seen other families accept a diagnosis and embrace the opportunity to parent

a child regardless of fetal conditions." The views of Dr. Bebbington expressed in his statement are

a glimpse into the biases and negativism of many obstetrical providers that provides fuel for the

epidemic of Down syndrome abortions.

32. The institutionalized medical pessimism which surrounds Down syndrome begins

with ACOG recommendations to offer prenatal genetic screening to all mothers. To be fair, it is

clear some parents have been able to better prepare for their future lives with a child with Down

syndrome when a prenatal diagnosis is made, though as the statistics reveal the majority of parents

opt for abortion. That aside, the determination of obstetricians to comply with the screening

recommendation implies that screening is routine, standard and should be done. This also assumes

proper informed consent regarding screening is given. The literature offers a concerning picture.

33. In 2018 Sheinis et al. reported that (in Canada) 29.5% of women did not know that

the Down syndrome screening test was optional and 10.2% of women underwent screening prior

to having been counseled.<sup>24</sup>

34. While non-directive counseling is a stated aim for prenatal counseling, the

prejudices of providers and educational materials invariably impact the provision of information

supplied to mothers and families. While primary care providers (pediatricians, family practitioners,

internists) and a variety of subspecialists are those most familiar with the medical and life course

of individuals with Down syndrome, maternal providers (obstetricians, maternal fetal medicine

specialists and genetic counselors) are the major contact for mothers and families early in the

pregnancy when they are attempting to determine whether a pregnancy should be continued or not.

There is a relative dearth of literature analyzing how effectively these specialties deliver non-

directive goals but what is published reveals this goal is not being achieved, and may not be

possible in the current environment.

35. In 2002 Roberts et al. published on the experience of 69 women receiving genetic

counseling in a genetics clinic. Of those surveyed, 83% reported they did not receive balanced

counseling regarding the quality of life for children with disabilities. Only 9% were offered contact

with a family with a child with disabilities.<sup>25</sup>

36. In a review of prenatal screening information pamphlets from Canadian prenatal

testing centers, Lawson et al. reviewed statements presenting information descriptive of Down

syndrome and a content analysis was carried out. The analysis revealed that 91% of the extracted

statements emphasized medical or clinical information about Down syndrome, whereas only 9%

of the statements relayed information pertaining to psychosocial issues. Nearly one half of the

statements portrayed a negative message pertaining to Down syndrome, while only 2.4% of the

statements conveyed a positive image of Down syndrome.<sup>26</sup>

37. Bryant et al. reported on the information about Down syndrome contained in 80

leaflets provided to pregnant women in the UK prior to serum screening. They demonstrated that

"the majority of information (89%) was of a medico-clinical nature, with 11% addressing other

issues associated with Down syndrome. The median number of sentences describing the condition

was one, with 33% of the leaflets containing no descriptive information. Overall, a negative image

of Down syndrome was conveyed by the leaflets, which contrasted with a more neutral image of

cystic fibrosis in the comparison study."<sup>27</sup>

38. The result of inadequate education regarding prenatal screening was discussed in

the New England Journal by Johnston et al. in 2017 stating, "Since the 1980s, prenatal screening

tests for a small number of traits including Down's syndrome have become routinized in ways that

can undermine informed consent. Specifically, studies show that women have undergone prenatal

genetic screening and diagnostic tests with only a limited understanding of the indications and

ramifications of the information that the tests can return. Medical anthropologists studying various

prenatal screening methods have found that routinization may also include the 'collective fiction'

that screening can improve fetuses' health and a 'collective silence' regarding the fact that a

positive screening result could eventually lead to a decision to abort."28

39. In 1994 Marteau et al. reported on the differing approaches of obstetricians, clinical

geneticists, and genetic nurses in counseling for prenatal diagnoses, using a scale of directiveness

in a survey that included 68 geneticists, 40 genetic nurses and 188 obstetricians. For Down

syndrome, 60% of obstetricians and 40% of geneticists reported counseling for termination of the

pregnancy in a directive manner.<sup>29</sup>

40. In 2012 Janvier et al. reported on obstetric and pediatric resident attitudes towards

abortion for a variety of prenatal conditions. For Down syndrome, 73% of obstetrical residents

would abort their child with Down syndrome. 43% of pediatric residents would also abort their

Down syndrome child.<sup>30</sup>

41. Ruth Marcus, an editor at the Washington Post, in a recent Washington Post opinion

piece consideringwhether she would have aborted a child with Down syndrome states, "Accepting

that essential truth is different from compelling a woman to give birth to a child whose intellectual

capacity will be impaired, whose life choices will be limited, whose health may be compromised.

Most children with Down syndrome have mild to moderate cognitive impairment, meaning an IQ

between 55 and 70 (mild) or between 35 and 55 (moderate). This means limited capacity for

independent living and financial security; Down syndrome is life-altering for the entire family.

I'm going to be blunt here: That was not the child I wanted. That was not the choice I would have

made. You can call me selfish, or worse, but I am in good company. The evidence is clear that

most women confronted with the same unhappy alternative would make the same decision."31

42. Ms. Marcus clearly states what is the central factor in deciding to abort a child with

Down syndrome. It is not the associated medical conditions which are treatable. It is the acceptance

of a child with cognitive impairment and intellectual disability and the negative impact many

believe it will have on a family's quality of life. What Ms. Marcus finds comfort in, the fact that

when confronted with a prenatal diagnosis of Down syndrome most women choose abortion,

should hardly be comforting. She is bolstered by the intolerance and subtle discrimination of a

culture towards those with intellectual impairment. We have created a discriminatory culture

incapable of seeing the right to life of the intellectually impaired, which prioritizes perceived

impact on the quality of life of those already living, and accepts the abortion of Down syndrome

infants, on a grand scale, as a morally acceptable choice.

43. The ongoing abortion epidemic for infants prenatally diagnosed with Down

syndrome may not be a legislatively forced sterilization program as advanced by Supreme Court

Justices writing, "Three generations of imbeciles are enough"<sup>32</sup>, but we are developing methods in

this country that have as their only purpose accurately identifying unborn infants with genetic

disorders. Unlike all other screening programs for a host of disorders, these prenatal genetic

screening programs offer no corrective intervention or earlier introduction of therapies to deal with

a condition.

44. The stated purpose of prenatal genetic screening and for those engaged in

developing these new and improved tests is to "avoid aneuploidy births." Others considering

prenatal screening and their perception of its intent have opined, "It is useful to reflect on the

missed opportunities for avoidance of birth defects."34 The opportunity missed, in the case of

Down syndrome, is elimination of a child. The "cure" for Down syndrome is the elimination of

the infant.

45. No mother is forced to abort her Down syndrome pregnancy in the US or Europe,

but a lack of proper informed consent in the performance of prenatal genetic screening, prenatal

testing which targets the identification of Down syndrome infants, a decided interest on the part

of public payers, healthcare officials and insurance agencies to reduce healthcare costs, counseling

which offers little humanity and focuses on intellectual impairment and medical conditions, a bias

in the obstetrical community to personally consider abortion for their own child with Down

syndrome and a legal environment in which law suits are filed on the basis of wrongful life when

a Down syndrome infant is born and parents not offered the opportunity to abort the child, have

created an environment which produces abortion rates for Down syndrome infants at epidemic

proportions.

46. "Genocide is a denial of the right of existence of entire human groups, as homicide

is the denial of the right to live of individual human beings; such denial of the right of existence

shocks the conscience of mankind, results in great losses to humanity in the form of cultural and

other contributions from these human groups and is contrary to moral law and to the spirit and

aims of the United Nations."35

47. The UN Genocide Convention Article 2 goes on to describe acts which constitute

genocide, these include "killing members of the group, causing serious bodily or mental harm to

members of the group, deliberately inflicting on the group conditions of life calculated to bring

about its physical destruction in whole or in part and imposing measures intended to prevent births

within the group."<sup>36</sup>

48. We have multiple examples of genocide throughout the course of human history.

What should we call it then when a group of individuals with an extra 21 chromosome, the

universal characteristic of some degree of intellectual disability, a variable spectrum of medical

conditions which are all treatable, a median life span of 47 years and a happy life, is targeted for

identification by a medical technology and healthcare provider community resulting in abortion

rates of 67% (range 61-93% after a prenatal diagnosis) in the US, and an even higher elimination

rate in European and Asian nations?

49. In the United States we have watched over the decades as individuals with Down

syndrome were sentenced to lives of despair in horrific institutions and denied commonly available

lifesaving treatments. These actions dramatically limited their survival. As a result of public

outrage and the advocacy of disability groups, the soft genocide of denial of care has generally

ended. Our willingness as a society to justify our eugenic instincts has inexorably led to the

development of more accurate and efficient means for controlling a population of individuals

whose common clinical characteristics is an extra 21st chromosome and some level of intellectual

disability. While Down syndrome infants, if they survive to be born, are generally offered a full

range of medical care and supportive services in their communities, genocide continues to be

waged against these infants through prenatal diagnosis and prevention of their birth.

50. As Dr. Bebbington illustrates, families now facing a prenatal diagnosis of Down

syndrome are counseled to consider their "circumstances, values, resources, and needs" in

determining whether to abort their child. Parents are, in the face of biased counseling, asked to

question whether the life of their child with Down syndrome is a life worth living. The environment

we have created in this country is well designed to deliver what it consistently produces, abortion

rates for Down syndrome infants that are at least 67% after a prenatal diagnosis.

51. The thought of caring for a Down syndrome child anticipated to have an uncertain

level of intellectual disability is stressful, anxiety provoking and certainly not the expectation we

have as parents anticipating a child's birth. Dealing with a prenatal diagnosis of Down syndrome

is a challenging and difficult experience, but the medical literature and parent reports clearly show

that families with a Down syndrome member believe they are better for it. Specifically, Skotoko

et al. all report parents loving (99%) and being proud (97%) of their child with Down syndrome.

About 79% said that their outlook on life was more positive because of their son/daughter with

Down syndrome. Brothers and sisters also had a favorable perspective, with nearly all reporting

love (97%) and pride (94%). <sup>23</sup> Older siblings reported being a better person (88%) because of their

brother/sister with Down syndrome. It is hard to imagine a survey of families with non-

intellectually impaired children could report greater love and impact of their child.

52. The Anti Discrimination Law for abortion in cases of Down syndrome in HB 126

is predicated on the belief that the perpetuation of a system which has systematically and efficiently

been eliminating a category of people from our society, based on their intellectual disability, is

inconsistent with the principles of justice which are the foundation of this nation. It is a necessary

step to attempt to return us to founding principles, to stand against disability discrimination and to restore our humanity.

I declare under penalty of perjury that the foregoing is true and correct to the best of my knowledge.

/s/ Martin J. McCaffrey, M.D.
Martin J. McCaffrey

Dated: August 19, 2019

#### References

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- 26. Lawson KL et al. The portrayal of Down syndrome in prenatal screening information pamphlets.J ObstetGynaecol Can. 2012 Aug;34(8):760-768. doi: 10.1016/S1701-2163(16)35340-3.
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# Martin John McCaffrey MD, CAPT USN (Ret) Curriculum Vitae

#### **Personal Information**

Martin J. McCaffrey 1008 Adams Mountain Rd Raleigh, NC 27614 (919) 619-1422

#### **Education**

Postdoctoral Fellow in Neonatology	University of North Carolina School of Medicine	July 1 1995	Neonatology
Pediatric Residency	Naval Hospital San Diego	July 1 1989	Pediatrics
M.D	Albany Medical College	May 22 1986	M.D.
B.S.	University of Connecticut	May 23 1982	Biology

# **Professional Experience and Employment History**

Perinatal Quality Collaborative North Carolina (PQCNC)	Director	7/2006-Present
Neonatologist	Professor of Pediatrics	8/2011-present
Neonatologist	Associate Professor of Pediatrics	7/2006-8/2011
Specialty Consultant to the Navy Surgeon General	Specialty Leader (CDR&CAPT)	7/1997-6/2006
Neonatologist Naval Medical Center San Diego	Division Head (CDR &CAPT)	7/1996-26/006
Neonatologist Naval Medical Center San Diego	Staff Neonatologist (CDR)	7/1995-6/1996
General Pediatrician Naval Hospital Guam	Department Head	7/1989-6/1992

### **Professional Experience and Employment History (cont)**

Pediatric Chief Resident Chief Resident 7/1988-6/1989 Naval Hospital San Diego

#### **Honors and Awards**

August 2010	Recipient North Carolina Perinatal Association's <i>Baby Bootie</i> Legislative Award - "honors outstanding legislators, individuals, or organizations who take leadership in sponsoring and supporting legislation as well as in funding and/or preserving funds that go to improve the health
	of mothers and babies."
June 2006	Meritorious Service Medal
May 2004	Promoted to CAPT US Navy
April 2004	Navy Commendation Medal
February 2003	Hero of Tricare; Selected by Assistant Secretary of Defense for Health Affairs
May 1999	Promoted to CDR US Navy
June 1998	UCSD Family Practice Residency Outstanding Teacher
June 1996	Teacher of the Year, Pediatrics Department, Naval Medical Center San Diego
March 1994	Promoted to LCDR US Navy
June 1992	Navy Achievement Medal
May 1985	Selected for Alpha Omega Alpha
July 1984	Military Health Professions Scholarship

#### **Bibliography**

Books/Chapters

Wheeler D and McCaffrey M. Resuscitation of the Newborn in the Delivery Room. Conn's Current Therapy, 2007 and 2008 edition.

Refereed Papers/Articles

Henderson ZT, Ernst K, Simpson KR, Berns SD, Suchdev DB, Main E, McCaffrey M, Lee K, Rouse TB, Olson CK. The National Network of State Perinatal Quality Collaboratives: A Growing Movement to Improve Maternal and Infant Health. J Womens Health (Larchmt). 2018 Feb;27(2):123-127.

McCaffrey MJ. Trisomy 13 and 18: Selecting the Road Previously Not Taken. Am J Med Genet C Semin Med Genet. 2016 Sep;172(3):251-6.

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Berrien K, Devente J, French A, Cochran KM, McCaffrey M, Horton BJ, Chescheir N.The Perinatal Quality Collaborative of North Carolina's 39 Weeks Project: a quality improvement program to decrease elective deliveries before 39 weeks of gestation. N C Med J. 2014 May-Jun;75(3):169-76.

Fisher D, Cochran KM, Provost LP, Patterson J, MetzguerK, Smith B, TestoniD, and McCaffrey MJ. Central Line Associated Bloodstream Infections in North Carolina NICUs. Pediatrics. 2013 Dec;132(6):e1664-71

Aliaga SR, Smith PB, Price WA, Ivester TS, Boggess K, Tolleson-Rinehart S, McCaffrey MJ, Laughon MM.Regional variation in late preterm births in North Carolina. Matern Child Health J. 2013 Jan;17(1):33-41.

McCaffrey MJ.Lethality begets lethality. J Perinatol. 2011 Sep;31(9):630-1; author reply 631-2.

Bookman L, Troy R, McCaffrey M, and Randolph G. Using quality-improvement methods to reduce variation in surfactant administration *QualSaf Health Care* doi:10.1136/qshc.2009.034967

Wood KS, McCaffrey MJ, Donovan JC, Stiles AD, Bose CL. Effect of initial nitric oxide concentration on outcome in infants with persistent pulmonary hypertension of the newborn. Biol Neonate 1999;75(4):215-24

Kinsella JP, Walsh WF, Bose CL, Gerstmann DR, Labella JJ, Sardesai S, Walsh-SukysMC,McCaffrey MJ, Cornfield DN, Bhutani VK, Cutter GR, Baier M, Abman SH. Inhaled nitric oxide in premature neonates with severe hypoxaemic respiratory failure: a randomized controlled trial. Lancet 1999 Sep 25;354:1061-5

McCaffrey MJ, Bose CL, Reiter PD, Stiles AD. Effect of L-arginine infusion on infant's with persistent pulmonary hypertension of the newborn. Biol Neonate 1995;67:240-243.

PAS Abstracts

Rachel G. Greenberg, Keith M. Cochran, P. Brian Smith, Barbara S. Edson, Martin McCaffrey. Effect of Dwell Time on Central Line Associated Bloodstream Infection in Infants (Platform)

Douglas E. Hardy, Sheree Kuo, Alan Picarillo, Keith Cochran, Barb Edson, Martin J. McCaffrey..Reduction of Neonatal Central Line Associated Blood Stream Infections in a National CLABSI Collaborative (NCLABSI Nation) (Poster Symposia)

Sheri Carroll, Brandi Page, Marty McCaffrey.Peer To Peer Site Visits in a State Collaborative Model To Reduce Neonatal Central Line Associated Bloodstream Infections. (Poster Symposia)

Nancy H. DeMaria, Keith M. Cochran, Tammy L. Haithcox, Tara B. Rouse, Martin J. McCaffrey. Improving Exclusive Human Milk Rates in Well Baby Nurseries Through a Collaborative, Hospital-Based Quality Improvement Initiative (Platform)

### **Teaching Record**

PQCNC Director (2009-Present)

All pediatric PQCNC Projects have been approved for Part IV MOC credit for participating physicians. Responsible for review of all participants and permitting MOC credit. Currently 425 physicians have received MOC through PQCNC sponsored projects.

Course Director (2016-Present)

Antibiotic Stewardship and Newborn Sepsis (ASNS) has begun development. Two learning sessions have occurred. Project will last 12 months and include 54 newborn and NICU centers. Expect 600 learners to be engaged directly in this work, including 100 physicians. The initiative has received IRB approval and has been submitted to the ABP for MOC credit approval. Attendees from across the state including Doctors, nurses, administrators, family members and family support staff.CEUs obtained through Wake AHEC

Course Director (2017-Present)

Alliance for Innovation in Maternal Healthcare (AIM): Reducing the Impact of Morbidity and Mortality Related to Maternal Hemorrhage). PQCNC is leading state AIM effort which includes NC OB GYN, NC AWHONN, and NC ACOG. Project will last 12 months and include 58 delivery hospitals. Expect 625 learners to be engaged directly in this work, including 100 physicians. Attendees from across the state including Doctors, nurses, administrators, family members and family support staff. CEUs obtained through Wake AHEC

Course Director (Feb 2013-Dec 2016)

Conservative Management of Preeclampsia (Series includes to date nine face to face Learning Sessions over 30 months, total of 425 learners. Attendees from across the state including Doctors, nurses, administrators, family members and family support staff. Course time totaled 63 hours. CEUs obtained through Wake AHEC

Course Director (Jan 2013-Dec 2015)

Neonatal Abstinence Syndrome (Series included Six Learning Sessions over 12 months, 40-80 attendees per session. Attendees from across the state including Doctors, nurses, administrators, family members and family support staff. Course time totaled 42 hours. CEUs obtained through Wake AHEC)

Course Director (Sept 2012)

Exclusive Human Milk Nursery and Exclusive Human Milk Well Learning Sessions (Two Learning Sessions, 60 attendees per session. Attendees from across the state including Doctors, nurses, administrators, family members and family support staff. Course time was 16 hours. CEUs obtained through Wake AHEC)

Lectures/Courses UNC

UNC Grand Rounds

"Making NC the Best Place to Give Birth and Be Born"

(Jan 2015)

UNC SOM Third Year
Genetics Track (2013-20)

"Down Syndrome", Annual, 1 hour

Genetics Track (2013-2014)

Neonatal Fellow PPHN, Meconium Aspiration, Hyperbilirubinemia (2 Lectures Annually)

Grand Rounds, Invited Continuing Education, Lectures Outside UNC

Annual Meeting American

Academy of
Prolife Ob-Gyns

"The Edge of Viability" Indianapolis, IN

March 2019

NC AWHONN Annual

Meeting

"Lives Worth Living: Trisomy 13 and 18." Greenville, NC

Washington, DC

February 2019

Hot Topics in Neonatology "If We Build It They Will Come:

Transforming Care via State Perinatal

Quality Collaboratives"

Dec 2018

Support for Trisomy (SOFT) "Lives Worth Living: Trisomy 13 and 18." Madison, WI

Annual Conference July

July 2017

UK Perinatal Conference "Lives Worth Living: Trisomy 13 and 18." Leeds, UK

July 2017

Alamance Regional "Antibiotic Stewardship and Newborn Alamance, NC

Medical Center Sepsis"

May 2017

Annual Meeting American "Lives Worth Living" Deerfield, IL

Academy of March 2017

Prolife Ob-Gyns

Proceedings published as "Lives Worth Living" in Issues Law Med. 2017 Fall;32(2):215-224.

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Grand Rounds Carolinas "Antibiotic Sto

Medical Center Sepsis"

"Antibiotic Stewardship and Newborn

Charlotte, NC

March 2017

*Invited Continuing Education/Lectures Outside UNC* (cont)

First Ireland Perinatal "A Tale of Two Trisomies: 13 &18" Dublin, Ireland

Conference February 2016

Annual Meeting American "Preterm Birth and Abortion" Washington, DC

Academy of February 2016

Prolife Ob-Gyns

Proceedings published as "The Burden of Abortion and the Preterm Birth Crisis" in

Issues Law Med. 2017 Spring;32(1):73-98.

Grand Rounds Columbus "Getting to Zero: Eliminating Columbus, GA

Regional Healthcare NICU CLABSI"

"Preterm Birth and Abortion"

March 2015

NC Pregnancy and Opioid "Transforming NAS Care Through Greensboro, NC

Exposure Project Quality Improvement"

March 2015

NeoConference "Transforming Perinatal Care Orlando, Fl

Pediatrix Annual Meeting Through Quality Improvement"

February 2015

Annual Meeting American "Preterm Birth and Abortion" Washington, DC

Academy of February 2015

Prolife Ob-Gyns

Annual Meeting of the "Excellence in the Care of NAS" Chicago, Il

Illinois Perinatal Quality "Transforming Perinatal Care"

Collaborative November 2014

Grand Rounds Cape Fear "QI, Breastfeeding Fayetteville, NC Valley Medical Center and Hypoglycemia"

Valley Medical Center and Hypog June 2014

South Carolina Neonatal "Spinning the Antibiotic Wheel Charleston, SC

Pharmacology Conference in the NICU"

Nov 2013

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Novant Perinatal "Transforming Perinatal Winston Salem, NC

Care Via QI" Sept 2013

SEAHEC Perinatal "Maternal Quality Wilmington, NC

Symposium Improvement" Sept 2013

Sept 2013

NeoConference "Transforming Via Orlando, FL

Pediatrix Collaboration" Feb 2013

VON Quality Congress "We're Having a PQCNC: Chicago, IL

Building a Collaborative"

Oct 2012

MA Perinatal Perinatal "Transforming Perinatal Boston, MA

Quality Collaborative Healthcare"
Oct 2012

APIC National "Eliminating CABSIs" San Antonio, TX

Meeting June 2012

Department of Pediatrics "Transforming Perinatal Healthcare Winston-Salem, NC

Wake Forest University in North Carolina"

June 2012

Grand Rounds – UNC

UNC Department of "Transforming Perinatal Healthcare" Chapel Hill, NC

Pediatrics February 2015

#### **Professional Service**

Discipline

2017-Present Medical Advisor to the Support for Trisomy (SOFT) Organization

2016-Present Co-Chair for the Center for Disease Control (CDC) National

Network of Perinatal Quality Collaboratives

2014-Present Board Member International Trisomy Alliance

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	(Supporting parents and medical providers in the care of infants and children with chromosomal trisomy disorders)
2013-Present	Appointed Member of the North Carolina Child Fatality Task Force, Pediatrician to the Child Fatality Task Force
2012-Present	Advisory Board of "Be Not Afraid", Support Organization for Families With Challenging Prenatal Diagnoses
2010-Present	Member NC Department of Public Health Hospital Acquired Infection (HAI) Committee
2010-Present	Member of Department of Public Health Subcommittee on Economic Impact of HAI
2010-Present	Member Expert Committee of the AHA's Health Research and
	Educational Trust (HRET) National NICU Panel for Stopping Blood Stream (SBI) Infections
2010-Present	Member National Perinatal Information Center (NPIC) Advisory Committee
2008-Present	Member NC Perinatal Health Committee
2008	Invited Expert Surgeon General's Conference for the Prevention of Prematurity, Washington, DC, June 2008.
2008-Present	Member Joint Commission Perinatal Core Measures Steering Committee
2007-Present	Member National Quality Forum (NQF) Perinatal Steering Committee
UNC Hospitals	
2016-Present	UNC PI and Co-Lead for WISER Study NIH Grant Leads at Stanford and Duke Universities
2016-Present	Leader NICU Team CLD
2015-Present	Faculty Co-Lead for UNC SOM Military Medicine Interest Group
2015-Present	Member UNC Newborn Nursery Triad

2014 Member UNC Hospitals Freedom Award Team

2010-2012 Co-Chair UNC Quality for Women and Infants Performance

Improvement Committee (QWIPIC)

2009-Present Member UNC Quality for Women and Infants Performance

Improvement Committee (QWIPIC)

#### Review Panels

2008-Present Reviewer for "Quality and Safety in Healthcare", 2008-Present Reviewer for International Forum on Quality and Safety in Health

Care

2008-Present Reviewer for "Journal of Pediatric Infectious Disease"

2008-Present Reviewer for "Pediatrics"

2004-Present Reviewer "American Family Physician" (Journal of the American

Academy of Family Practice)

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